The development and efficiency of the support group in Taiwan MND Association

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Background of study

- Difficulties facing the diagnosis of ALS/MND
- Meet with other patients or families
- Peer support group since 2005
The purpose of study

• To understand the experience and meaning of attending the group
• To adjust the support group service in the future
Development of the group (1)

• Start from 2005
  – a counselor as the leader and a social worker as the co-leader
  – once a week for eight sessions
  – Patient and family member in same group
  – Patients in different stages of illness
  – 6 to 8 people in one session
Development of the group (2)

• 2010
  – 2 hours once a month for 8 months in a row

• 2013
  – New members and old members in different groups
Methods- Data collection

• 5 patients and 4 family members continuously attended the support group more than one year
• semi-structured interviews
• single interview, average time of 1.5 to 2 hours
Methods- Data analysis

• interviews were recorded and then type-written precisely

• open coding → grouped into main concepts → axial coding → developed into categories
Motivation of continuously attending the peer support group

- To meet with other patients and learn more about the disease
- To share and learn how to cope with the disease better.
- Value the time spent with other patients.
- To help and encourage other patients particularly the new diagnosed patients so they can adjust quicker
Results and Discussion (2)

• Gains/ Benefits
  – Information exchange
  – Feel encouraged, comforted, cared and more confident
  – Have chances to express feelings
  – Something to look forward to
  – Improve the communication within family
  – Support each other
Results and Discussion (3)

- **Process of psychological adjustment**
  - nervous, depressed and sad
  - seek information, try to overcome then plan for the future
  - Accept (religion helps to let go)
  - Living with the disease peacefully
  - Devote to help others (new members and the public)
Results and Discussion (4)

• Suggestions for the group
  – continue held the support group
  – Find out reasons of stop attending the group
  – new members and old members in the same group, new members get more help
Conclusions

• With the facilitation of the professional leader, the group has a sense of camaraderie; members share practical issues in a very meaningful way

• The group helped members developing coping strategies
• help the new patients and their families to know the disease better and adjust better. Meanwhile, the old members feel encouraged by helping others
• social worker should check up on members stop attending the group and continue follow up
• Future research
  – Reasons for stop attending the group
  – Meaning for different stage illness
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THANKS FOR LISTENING!